Atomic Energy Control Board
P.O. Box 1046
Ottawa Canada
K1P 5S9

Commission de contrôle de l'énergie atomique
C.P. 1046
Ottawa Canada
K1P 5S9

INFO-0269

MORBIDITY FOLLOW-UP FEASIBILITY STUDY

by

M. Carpenter
Statistics Canada

A research report prepared for the
Atomic Energy Control Board
Ottawa, Canada

February 1988

Canada

Research report

88-06130/

MORBIDITY FOLLOW-UP FEASIBILITY STUDY

A study prepared by Maureen Carpenter, Statistics Canada, Health Division, under contract to the Atomic Energy Control Board.

ABSTRACT

The report reviews the available sources of data within Canada for undertaking morbidity follow-up studies to both supplement and complement studies using Canadian mortality data. Such studies would permit earlier detection and more sensitive measures of differences in risk for exposures to radiation and allow timely measures to be taken to minimize any occupational and environmental health risk to radiation workers.

The technical feasibility of using these sources was reviewed using the criteria of adequate personal identifying information, automation of data records, file size and the accuracy of the morbidity diagnosis information. At the present time certain of the provincial cancer registry files meet these criteria best. A work plan was prepared suggesting a morbidity pilot study to clarify the role of occupational factors in the incidence of cancer among radiation workers using the Alberta Cancer Registry file and the National Dose Registry (NDR) file of radiation workers. For the longer term a full cohort study using the National Cancer Incidence Reporting System (NCIRS) and the NDR workers as the study population would provide information on all radiation workers on a national basis. A work plan was prepared and some initial format conversion of historical data was undertaken to begin developing the NCIRS into a data base suitable for long-term health studies.

DISCLAIMER

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RÉSUMÉ

La présente étude examine les sources de données existant au Canada pour l'exécution d'études de suivi sur la morbidité afin de compléter les études utilisant les données canadiennes sur la mortalité. De telles études permettraient une détection plus rapide et l'établissement de mesures plus valables des différences de risque en cas d'irradiation, ainsi que l'établissement de mesures plus opportunes pour minimiser tout risque professionnel et environnemental pour la santé des travailleurs sous rayonnements.

La faisabilité technique d'employer ces sources a été revue en utilisant les critères d'identification personnelle appropriée, d'automatisation des fichiers de données, de taille des fichiers et de précision des diagnostics. À l'heure actuelle, certains fichiers de registres provinciaux des cas de cancer répondent le mieux à ces critères. Un plan de travail qui propose une étude pilote sur la morbidité a été préparé afin de préciser le rôle des facteurs professionnels sur le nombre de cas de cancer chez les travailleurs sous rayonnements grâce aux registres des cas de cancer de l'Alberta et au Fichier dosimétrique national (FDN) pour ces travailleurs. À plus long terme, une étude de cohorte complète ayant recours au Système national de déclaration des cas de cancer (SNDCC) et aux travailleurs du FDN comme population à l'étude fournirait des renseignements sur tous ces travailleurs à l'échelle nationale. Un plan de travail a été préparé et une conversion initiale du format des données d'archives a été entreprise afin de commencer à transformer le SNDCC en une base de données convenant à des études à long terme sur la santé.

MORBIDITY FOLLOW-UP FEASIBILITY STUDY

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1. **BACKGROUND**

Information on risks to human health depends critically on the availability of quality data. In Canada computerized record linkage has been increasingly used to conduct epidemiological studies on long-term health effects including occupational and environmental studies and studies of hazards in the workplace.

The majority of these studies examine associations between individual exposure to potentially hazardous circumstances and mortality. The Canadian Mortality Data Base (CMDB) and record linkage system at Statistics Canada are being used in many studies of the relationship between occupation and cause of death. These studies have resulted in substantive contributions to knowledge concerning the relationship between exposure to certain hazards and risks of death.

It is important, however, to be able to identify those ill-health conditions which do not result in death and there is a serious deficiency in major sources of national health related data bases in the area of morbidity data. Morbidity data, especially data on chronic disease, would greatly assist and both complement and supplement mortality (death) data available through the Canadian Mortality Data Base by providing the means for an earlier detection of potential hazards such as ionizing radiation or chemicals and a more sensitive

measure of differences in risk. This would be important for development of public policies, regulatory assessment, health promotion and safety standards, and health research.

An overall program objective was to determine the feasibility of using morbidity data in Canada for long-term health research studies.

As cancer is a leading cause of serious morbidity and mortality in Canada and is projected to increase in public health importance for the forseeable future, it was determined that one major long term excellent potential national data source would be the National Cancer Incidence Reporting System (NCIRS). This was established in 1969 at Statistics Canada in collaboration with provincial cancer registries and the National Cancer Institute of Canada. It includes cancer incidence recorded by each of the provinces. Only since 1985 has the Ontario data been available for inclusion in this system with data provided so far from 1981. (Identifying data from Ontario to allow epidemiological studies still needs to be supplied.) One of the aims of this system is to provide a data base to facilitate epidemiological studies including identification of regional differences, inequalities and special needs. To achieve this goal certain improvements are necessary in the data file.

2. OBJECTIVES

The objectives and scope of the work under this project were:

2.1 Morbidity Study

2.1.1 to prepare a work plan to undertake a technical feasibility study to use at least one existing computerized morbidity data file for follow-up of a selected population study group with exposure to ionizing radiation.

2.1.2 to obtain information on the availability of relevant national or provincial computerized morbidity or chronic disease data files potentially suitable for record linkage to follow-up health effects and risks for specific groups of people exposed to potentially hazardous occupational or environmental substances, such as ionizing radiation.

2.2 National Cancer Incidence File Development

2.2.1 to prepare a work plan for developing the National Cancer Incidence Reporting System (NCIRS) into a data base suitable for record linkage and future long-term health studies, e.g. for descriptive studies to give geographical or ethnic patterns, trends and changes over time, or to detect clusters of leukemia or other cancers; and for analytical studies of cohorts for exposed occupational groups such as radiation workers, or case-control studies of rare cancers.

2.2.2 to begin the necessary work to convert the "historical" file records in the NCIRS for years prior to 1979 to the new format in use from 1979.

3. METHODOLOGY

3.1 A general review was undertaken of the type and availability of relevant national and provincial computerized morbidity data files (1-7). In addition to reviewing the hospital and morbidity data for Canada available in Health Division, contact was also made with (i) Labour Canada, Occupational Safety and Health; (ii) Health and Welfare Canada (iii) Ontario Ministry of Health and (iv) Canadian Centre for Occupational Health and Safety.

3.2 For the initial pilot study, it was originally decided to investigate the possible use of the Ontario Cancer Incidence file as the morbidity data source and the nominal roll of Ontario miners, consisting of approximately 55,000 uranium and non-uranium miners as the study group.

Specific contact was therefore made with the Ontario Cancer Research and Treatment Foundation (OCTRF) to request access to their data files and to the Ontario Workers Compensation Board (WCB) to investigate the possible use of their nominal roll of Ontario miners.

3.3 A review of the National Cancer Incidence File was undertaken to determine the action needed for its development into a morbidity data source for epidemiological studies.

4. RESULTS

4.1 Sources of Morbidity in Canada

The type of morbidity data giving details of ill-health effects presently gathered in Canada includes:

hospital separation records, Hospital Medical Records Institute (HMRI) records; disease registers of cancer incidence, congenital anomalies, renal failure, and tuberculosis; records of notifiable diseases; poison control centre records; medicare records; physician records; individual company health records Workers Compensation Board records; mental health records; and health survey records. Appendix A, Table I lists the relevant morbidity source, the type of information available, and the publication or source from which further information can be obtained. Supplementary information is given in Tables 2 and 3.

As will be seen, any program of morbidity research will have to depend to a large extent upon the provincial health information systems as sources of basic data.

The technical feasibility of using these sources will depend on the adequacy of the personal identifying information, the degree to which the files are automated, their size, and the accuracy of the diagnosis information. Adequate personal identifying information is needed to ensure accurate study follow-up so that cases of mistaken identity will be rare. Automated files are needed to allow national follow-up studies of very large groups over long time periods for pin-pointing potential public health trouble areas and delayed chronic diseases which are now the major health

concerns. Size will need to be considered in determining the type and capacity of equipment and facilities needed. The accuracy of the diagnostic information needs to be sufficiently specific and consistent to allow correct definition of the disease and diagnosis comparisons.

Other relevant factors that will need to be considered are i) the cost, but this should always be weighed in relation to the expected multiplicity and magnitude of the uses, and ii) the privacy aspects and confidentiality of the records; for this data custodians will need guarantees of appropriate safeguards, security arrangements and non-release of individual identified data, together with either confirmation of the individual's permission to use the data or information that the public interest or good clearly outweighs any invasion of privacy.

4.2 Suggested Morbidity Pilot Study

4.2.1

a) It was advised that a formal submission must be made in the prescribed format to obtain agreement from the Ontario Cancer Research and Treatment Foundation (OCTRF) for the access and use of their records. The procedure for requesting agreement for use of the record file was obtained. However, discussions by telephone and at meetings between OCTRF representatives and

Statistics Canada, Health Division representatives revealed there would be some time delays likely in acquiring use of identified data at this time.

b) At the same time conversations were held with the Ontario Workers Compensation Board to request the use of their Ontario miners' file for this pilot study. At that time a delay was being experienced in the updating of the Ontario Miners' Mortality study at Statistics Canada and some further delay in obtaining use of the file for a morbidity study was therefore also likely. In any case for the Ontario Miners' file as the study file, only an Ontario or national file would be feasible to use as the morbidity file and the only practical one at the present time would be the OCTRF file.

4.2.2 Under these circumstances alternative files were considered. The Atomic Energy Control Board representatives were consulted and the decision was made to consider the feasibility of using the Alberta Cancer Registry file and the National Dose Register file, or a part of this, as the morbidity file and study file respectively. Informal agreements were obtained from the two agencies concerned and formal letters of request for access to and use of these two files were sent in December 1985 to the Alberta Cancer Registry and the Radiation Protection Bureau, Health and Welfare Canada.

Agreement from both agencies has been received for the use of these files for a pilot cancer morbidity study.

4.2.3 An initial work plan for undertaking this study has been set up as shown in Appendix B.

4.3 National Cancer Incidence File

4.3.1 A proposal to develop the National Cancer Incidence Reporting System into a facility for epidemiological follow-up studies and cancer surveillance was prepared in February 1985. The proposal and general work plan is attached (Appendix C).

4.3.2 The proposal was discussed by Statistics Canada management and the Directors of provincial cancer registries.

4.3.3 In December, 1985 a formal review of the NCIRS took place sponsored by the National Cancer Institute of Canada (NCIC) and Statistics Canada, and a report and recommendations were made in January 1986. The key recommendation was that a National Council on Cancer Registries be formed representing all participants in the National Cancer Incidence Reporting System, and that it be charged with the responsibility of ensuring the development of a fully functional Canadian Cancer Registy. Plans are now underway to establish this Council to include representation from each of the provincial registries and Statistics Canada. Initial funding for facilitating the formation of the National Council has been provided for a 3 year period (1986-1989) by

the National Cancer Institute of Canada (NCIC). Consideration and progress is also being made on implementing the other recommendations of the Review Team.

4.3.4 Conversion of historical cancer data to the format of the current cancer file for 1979 and later years, as a first objective in the development of the NCIRS into a Canadian Cancer Registry, was accomplished for two years, 1978 and 1977.

This work involved:

- recoding a variety of fields on the historical file to current codes
- reformatting the file to the new format
- editing the reformatted file in the current processing system
- correcting (a few) errors detected during editing.

The momentum initiated by this contract has stimulated work to continue on this conversion at Statistics Canada since the end of this particular contract. The historic file has now been converted back to 1970.

SUMMARY

Some of the main sources of morbidity being collected and maintained in computerized form in Canada with sufficient identification information to permit record linkage for investigating health risks, are the cancer incidence records maintained by the Cancer Registries in each province. Among these, the identification data and quality control also varies.

Experience and quality assessment has been undertaken within Statistics Canada with the Alberta Cancer Registry file. It is therefore proposed that this file be used as the morbidity source for an initial pilot study. The follow-up of National Dose Registry workers as the study group is proposed as this would yield useful information for clarifying the role of occupational factors in the incidence of cancer among radiation workers. Statistics Canada's experience with the National Dose Register file in preparation for the study of the MORTALITY of radiation workers would be an advantage in organizing this study.

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5. Third Annual Report, 1980-81, Ontario Advisory Council on Occupational Health and Safety, Appendix 6.

6. Disease Registries in Canada, Chronic Diseases in Canada, Health and Welfare Canada Vol. 6, No. 4. March 1986.

7. Notification and Surveillance of Occupational Diseases in Canada and Other Countries, Canadian Centre for Occupational Health and Safety, P84-3E, June 1984.

TABLE I

MORBIDITY DATA SOURCES IN CANADA

Hospital Separation Records	Statistics Canada
Special Residential Care Facilities	Statistics Canada
Hospital Medical Records Institute (HMRI)	Ontario Medical & Hospital Associations (OMA & OHA)
Professional Activities Services (PAS)	Alberta & New Brunswick
Med-Echo System	Quebec
Medicare Data	Each Province
Workers Compensation Boards (WCB's)	Each Province
Poison Control Centres	Health & Welfare Canada
Company/Industry Records	Individual Organizations
Mental Health	Statistics Canada
Physician Data	Individual Physicians
National Cancer File	Statistics Canada
Provincial Cancer Registers	Each Province
Renal Failure Register	Statistics Canada
Tuberculosis Reporting System	Statistics Canada
Congenital Anomalies Register	Health and Welfare Canada
Notifiable Diseases	Statistics Canada
National Health Surveys	Statistics Canada/ Health & Welfare Canada

TABLE I

MORBIDITY DATA SOURCES IN CANADA - DETAIL

Source		Information	Reference
Hospital Morbidity Hospital Separation Records Statistics Canada	i)	Source records collected by the provinces from individual hospitals through hospital admission/ discharge forms.	Statistics Canada Cat. 82-206 (Annual)
	ii)	Data are for 1,250 Canadian hospitals amounting to approximately 4 million records each year.	
	iii)	Data is collected by "event" not individual. Multiple entries would need to be "internally linked" to obtain a patient profile.	
	iv)	Inadequate identifying information is supplied to Statistics Canada. This is held by individual hospitals. It is deleted from original tapes in the province of origin.	
	v)	Inpatient data only; outpatient and emergency patients are excluded.	
	vi)	Diagnoses are available coded with the International Classification of Diseases (ICD) codes. Only one diagnosis per separation is published; others may be extracted from the computer file.	
Special Residential Care Facilities Statistics Canada	i)	Source records obtained direct from individual facilities except for Alberta and Quebec where records are collected and supplied by the province.	Statistics Canada Cat. 83-236 (Annual)
	ii)	Voluntary reporting program: 4,884 facilities (1982-83), 65% of the total beds are reported by 55% of the facilities for 132,000 patients, 95% occupancy.	
	iii)	Summary information only by province, age, sex and principle characteristics.	

	iv)	General diagnosis only ie. physically handicapped, mentally handicapped, aged, alcohol/drug addiction, etc.
	v)	No individual identification.
Hospital Medical Records Institute (HMRI) (see attached Table 2, page 24)	i)	One of the most comprehensive health data collection systems established jointly by the Ontario Medical Association and the Ontario Hospital Association in 1963.
	ii)	Collects 53% of health status records from Canadian Hospitals (all Ontario and P.E.I. and about 70% of Saskatchewan and B.C. hospitals. In Quebec some hospitals are also joining the system).
	iii)	No personal identifiers are captured so far, only the case chart number.
	iv)	Specific diagnoses collected and coded.
	v)	As for the hospital separation records, inpatient information only is collected: outpatients and emergency patients are excluded.
Professional Activities Services (P.A.S.) (see attached Table 2, page 24)		Provides similar services as HMRI in the provinces of Alberta and New Brunswick.
Med-Echo System (see attached Table 2, page 24)		Provides similar services as HMRI in Quebec.
Medicare Data	i)	Type and extent of data collected varies widely among provinces.
	ii)	Data is collected from physicians for economic (payment) purposes not disease diagnosis. Diagnoses are therefore often too general for epidemiologic studies.
	iii)	Use of some provincial records is possible e.g. Saskatchewan.

	iv)	Health care insurance files are very large (Ontario - 1.4 million) and would therefore be very costly to use.	
	v)	Identification information variable by province.	
	vi)	Linkage with medical data files e.g. HMRI would be needed to bring together identification and diagnosis (Ontario is doing this).	
rkers Compensation ards (WCB's)	i)	Data supplied by all 10 Provincial Boards to Statistics Canada.	Statistics Canada Cat. 72-208 "Work Injuries" 1983-85.
	ii)	Workers' Compensation covers work injuries and occupational illness for about 80% of the employed labour force in Canada. There is no legal requirement for self employed people who can choose to contribute or not. Time-lost injuries illnesses (including fatalities) total about 500,000 (1984 data).	
	iii)	Records are by 'event' and would need to be "internally linked" for information by individual.	
	iv)	A claim has to be submitted and varying criteria are applied province to province for acceptance.	
	v)	No individual identifying information is supplied to Statistics Canada. This is held by individual WCB's.	
	vi)	Diagnosis is specified in general terms according to a specified national standard. Some WCB's als use more specific ICD codes.	
ison Control Centres	i)	Data is collected and notified by hospitals and health centres across the country to a central system at Health and Welfare Canada.	Health and Welfare Canada: Poison Control Statistics.
	ii)	Data are often incomplete or poorly documented.	

	iii) Most information is on the home use of chemicals or drugs. No occupation information is available.		
	iv) Diagnoses of the toxic intake are often vague.		
Individual Company Records	i) Data are kept where there is exposure to hazardous materials: this is a regulatory requirement for specified substances which vary by jurisdication.		
	ii) Records are held of sick leave taken.		
	iii) Health status of employees is maintained and diagnoses held, in some cases.		
	iv) Individual identification is available where records are kept, although this is sometimes inadequate.		
	v) Exposure data is held, in some cases.		
Mental Health Statistics Canada	i) Data is received from each province, who obtain it from individual hospitals.	Statistics Canada Cat. 83-204	
	ii) Includes data from general hospitals (80%) and psychiatric hospitals (20%). Other summary information is also included under residential care facilities (noted above).		
	iii) No individual identifying information is received, as for hospital separation records above.		
	iv) Inpatient care information only. No outpatient or emergency information, which are now likely to be the majority of cases.		
	v) Diagnosis information coded (ICD codes).		
Physician Data	i) Records of individual physicians.	Individual Provincial Health Ministries	
	ii) Not centralized or summarized.		
	iii) Very large numbers involved: millions of records.		

	iv)	Data quality variable.	
	v)	Diagnoses often not specific enough for long term health studies.	
DISEASE REGISTRIES			
Provincial Cancer Registers	i)	Records of all incidence of cancers within each province.	Individual Provincial Cancer Agencies
	ii)	Detailed information on diagnoses and treatment.	
	iii)	Collected by provincial registries from various sources within the province.	
	iv)	Data quality variable among the provinces. Improvements and standardization co-ordinated through NCIC Committee on Records and Registries.	
	v)	Records kept on an "event" basis. Need for "internal linkage" to bring together records by individual for health studies.	
	vi)	Reporting is a legal requirement in 4 out of 10 provinces (Nova Scotia, Saskatchewan, Alberta and B.C.).	
	vii)	Informal agreements for notification to Statistics Canada for a central system.	
National Cancer Incidence Reporting System (NCIRS), Statistics Canada	i)	National register for cancer incidence data in Canada.	Statistics Canada "Cancer In Canada" Cat. 82-207 Annual since 1969.
	ii)	Information received from provincial registries excluding Ontario from 1969. Ontario records (excluding identification data) received in 1985 from 1981. Formal agreements for transfer of data between the provinces and Statistics Canada are presently being prepared.	
	iii)	Important potential source for epidemiology and other health studies.	
	iv)	Data quality variable among the provinces. Greater uniformity of records in format and coding and	

		improved completeness of coverage needed in some areas. Standardization being co-ordinated through NCIC Committee on Records and Registries.	
Renal Failure Register, Statistics Canada	i)	Voluntary national reporting program established in 1981 as a joint project of Statistics Canada, Health and Welfare Canada and the Kidney Foundation of Canada.	Canadian Renal Failure Register Report, Kidney Foundation of Canada
	ii)	Data received from 72 centres across Canada. 100% reporting being achieved on incidence from 1981.	
	iii)	Individual identification for all records since 1981.	
	iv)	Diagnosis and treatment held for all records from 1981.	
	v)	Total cases 7,214 (1984) i.e. approximately .0003% of the Canadian population.	
Tuberculosis Reporting System Statistics Canada	i)	National register for TB incidence (new and reactivated) in Canada.	Statistics Canada Tuberculosis Statistics; Morbidity and Mortality Cat. 82-212 Annual (Since 1937)
	ii)	Records held in computerized form from 1951 but some records destroyed. (Computer tapes useable from 1956).	
	iii)	Information received from provincial directors of TB Control.	
	iv)	A notifiable disease for all provinces.	
	v)	Identification data held. However not supplied by Quebec since 1984, nor by Ontario for 1979-82 and 1984.	
	vi)	Diagnosis information held.	
	vii)	100% reporting. Total new cases 1985 - 2,144 i.e. .0001% of total Canadian population (8.5 cases per 100,000).	

Congenital Anomalies Register, Health and Welfare Canada	i)	Refers to birth defects	
	ii)	Voluntary reporting program from 1966. 8 participating provinces from 1981.	
	iii)	Covered approximately 70% of the births in Canada	
	iv)	Intermittent collection. Data is incomplete. No occupation is held for mother or father.	
	v)	Register temporarily suspended 1986 (except in Manitoba) for redesign.	
	vi)	Better individual identifying information needed for follow-up studies.	
Notifiable Diseases: Statistics Canada	i)	Includes data on 40 diseases (including TB) provided every 4 weeks by provincial departments of health, from reports received from local medical officers of health, from notifications by private physicians. Certain diseases are not well reported.	Statistics Canada Cat. 82-201 Annual (since 1922). Discontinued in 1978. From 1979 - 4 weekly tabulations and Annual tabulations.
	ii)	Summary information only of number of cases for each disease by age group, sex and province.	
	iii)	No individual identifiers.	
Health Surveys Statistics Canada, Health and Welfare Canada (see attached Table 3, page 25)	i)	National sample surveys of the population.	See attached list
	ii)	Many do not capture adequate individual identifiers for follow-up over time.	
	iii)	For the Nutrition Canada Survey, 1972 and the Canada Health Survey, 1978/79: individual identifiers were collected in machine readable form. Mortality follow-up has been conducted.	
	iv)	The Canada Fitness Survey, 1981, the Canadian Health and Disability Survey 1983-84, and the General Social Survey, 1985 did not capture adequate identifiers to allow for long-term follow-up health assessments.	

v) "Exposure" data is captured through self reporting.

vi) Diagnostic information is self-reported.

TABLE 2
(see Table 1, Page 17)

Appendix A

HOSPITAL ADMISSION-SEPARATION RECORDS

	Hospital Medical Records Institute (HMRI)	Professional Activities Services (PAS)	Own System
British Columbia	Part HMRI	-	Part Own
Alberta	-	PAS	-
Saskatchewan	Part HMRI	-	Part Own
Manitoba	-	-	Own System
Ontario	HMRI	-	-
Quebec	-	-	Own System (Med-Echo)
Nova Scotia	Part HMRI	-	Part Own
New Brunswick	-	PAS	-
P.E.I.	Part HMRI	-	Part Own
Newfoundland	Part HMRI	-	Part Own

TABLE 3 (see Table 1, Page 22)

Appendix A

NATIONAL HEALTH SURVEYS

	Numbers Available for Health Studies	Adequate Individual Identifiers Captured	Publication
Nutrition Canada Survey, 1972	13,000	Yes	Nutrition: A National Priority: Report By Nutrition Canada to Health and Welfare Canada, Nov. 1973
Canada Health Survey, 1978-79	31,000	Yes	Statistics Canada Report, Cat. 82-538E, June 1981.
Canada Fitness Survey, 1981	23,500	No	Fitness and Lifestyle in Canada, Canada Fitness Survey, Canada Fitness and Amateur Sport May, 1983
Canadian Health and Disability Survey, 1983-84	27,000	No	Statistics Canada, Main Report Cat.82-555E/F, July, 1986 Highlights, Cat.82-563E/F, June 1985.
Health Promotion Survey, 1985	20,000	No	Health and Welfare Canada. Publication in process.
General Social Survey 1985	11,300	No	Statistics Canada. Publication in process.
Hypertension Awareness Survey, 1985-86	3,000	No	Health and Welfare Canada. To be published.
Health and Activity Limitation Survey, 1986	123,700	Yes	Statistics Canada. Publication in 1988.

Appendix B

WORK PLAN For Proposed Morbidity Pilot Study Using the National Dose Register File and the Alberta Cancer File

The study is proposed to be carried out over a period of two years. The case-control methodology is selected where those with the disease (cases) are compared with similar individuals but without the disease (controls), and detailed past history of occupational radiation exposure, as noted by the National Dose Register, will be obtained for both cases and controls.

A. Initially a Pilot Study is suggested using small numbers to test the linkage and examine the methodology.

A number of cases will be selected from the Alberta Cancer Registry File and the National Dose Registry, Alberta registrants, distributed by age and sex and for a certain number of years. Matching controls (by age and sex) will be selected from the National Dose Registry, Alberta registrants who do not appear on the Alberta Cancer Registry file. Dose exposure histories will be obtained for all cases and controls from the National Dose Registry file records. The experience with the methodology and the results will be documented.

The kinds of information and availability of identifiers needed to ensure the success of the linkage to carry out this study are given in Appendix B, Tables 1 and 2.

B. Following this a larger scale study is proposed, again using the case-control methodology but with larger numbers of cases and controls and a longer time period. The Alberta Cancer Registry file and the whole National Dose Registry file will be used. The results will demonstrate the linkage obtained and provide details of types of cancers and differences in occupational exposure histories for cases and controls.

C. For the future, when the NCIRS is sufficiently developed, a full cohort study is proposed using the developed NCIRS as the morbidity file and the NDR workers as the study population.

Table 1

Appendix B

Information and Availability of Identifiers
In the Alberta Cancer Registry File
And the National Dose Registry File
Of Use for Linkage

	Alberta Cancer File				NDR			
	Characters on Records		Availability %		Characters on Records		Availability %	
Social Insurance No.	9		–		9		69.2	
Surname	10		99.9		12		100.0 Rest of	
First Given Name	9	Initial	98.9		9	Initial	97.1 Name	44.44
Second Given Name	7	Initial	22.2		7	Initial	33.7 ——	7.7
Father's Surname	–				–			
Maiden Surname	10		1.6		–			
Birth – Year	4		98.1		2		84.6	
– Month	2		77.5		2		48.8	
– Day	2		76.4		2		45.5	
Birth Prov/Country	–		–		2		11.3	
Sex	1		100.0		1		88.2	
Marital Status	1		35.9		–			
Residence – Province	2		55.1	Prov. of Employment	1			
– County	2				–			
– Locality	3				–			
Year of Death	2	Yr. of Diagnosis	82.2	Date of Last Dose	2		100	
– " –	1	Patient Status (D)	39.7					
– " –	1	Vital Status Source Year	29.3					
Occupation	–				4			
Employer Identification	–			Group No. – Prov.	1		99.8	
				– Type of Employer	1		93.0	
				– Kind of Service	1			
				– Serial No. (Employer Identifier)	5		100.0	

Appendix B

Table 2

Kinds of Information and Comparisons Used for Linkage

Information or Comparison	Remarks
Surname comparisons	Includes comparisons with maiden and alternate last names where present.
Given Name comparisons	Includes spouse's names/initials where present
Birth Date comparisons	For degree of agreement
Birth Place comparisons	Not available at present, but could be in future.
Sex	
Place of Residence comparisons	Includes province of residence (Alberta) versus province of employment (NDR)
Last Known Alive Year, and Vital Status Source	These indicate alive status and would include if currently employed.

APPENDIX C

DEVELOPMENT OF THE NATIONAL CANCER INCIDENCE FILE

A. General Objectives and Description

The main objective of the proposed project is to develop the national cancer incidence file into a facility for epidemiological follow-up studies and cancer surveillance.

The National Cancer Incidence Reporting System (NICRS) was established in 1969 in collaboration with provincial cancer registries and the National Cancer Institute of Canada with the aim of studying cancer patterns and trends and conducting epidemiological cohort studies and ongoing cancer surveillance. To realize the latter objectives, the file needs to be organized into a format that permits efficient linkage.

Impact

The developed file would complement the existing mortality data base and the to be developed morbidity data base. Use of the cancer incidence file, in conjunction with the other facilities, would greatly increase the potential for detecting and measuring occupational, environmental and life-style cancer risks in the population. Compared with mortality records, the strength of cancer incidence records lies in that they provide a more sensitive measure of differences in risk for a number of reasons which include that (a) all cancers, not only those that lead to death, are recorded, (b) earlier detection of hazards is possible because the date of diagnosis may precede the date of death by many years for some cancers, and (c) the diagnostic information is very precise, including detail (such as histological type of cancer) that may be important in assessing aetiology.

General Benefits of Project:

- To develop facilities for investigating cancer risks using incidence records as a complement to mortality records.
- To add to the body of knowledge of occupational, environmental and life-style health risks.

- To provide more sensitive, meaningful and timely information on health effects of exposure to health hazards.
- To assist in identifying areas of occupational and environmental health risk requiring public health and policy-making actions.

Other Benefits

The work will result in improvements in the quality of the data already on the data base and of incoming data.

B. Specific Objectives

1. *To set up a consolidated cancer incidence file that has a uniform format for all data years.*

This involves:
- converting the 'historical' file for 1969 to 1978, which differs in format and coding structure used from the current file (1979 and onwards), to the format of the current file;
- editing and verifying the converted file.

Benefits:

- Facilitate analysis of data and tabulation of data for special requests;
- Identification of gaps and inconsistencies in the file;
- Facilitate further development of file.

2. *To prepare the consolidated cancer incidence file for linkage by:*

- setting up name fields in a manner that facilitates linkage;
- creating alternate records for persons with alternate or previous names (aliases, maiden names);
- assigning NYSIIS or other name codes to facilitate linkage:
- analyzing contents of other fields used in linkage and upgrading their quality.

Benefits:

- Facilitate efficient linkage.

3. *To internally link the cancer incidence file to bring together records for patients with more than one primary cancer and to assess the feasibility of routinely linking incoming records to records already on the file by:*

- linking records within the file;
- eliminating duplicate registrations (in consultation with provincial cancer registries);
- cross-referencing valid multiple records for the same person within the cancer system;
- creating a searchable microfiche of cancer incidence records.

Benefits:

- Improvement in quality of file due to elimination of duplicates;
- Enhancement of analytic capacity by permitting study of multiple cancers (which may have a common aetiology) in the same person;
- Facilitates small follow-up studies through use of microfiche;
- Facilitates large scale follow-up studies involving computerized linkage.
- Facilitates linkage to the mortality file to establish survival rates.

4. *To conduct a feasibility study of linking the cancer incidence file with the mortality file. This would ultimately yield survival information for cancer patients, would improve the completeness of the file and permit evaluation of the quality of diagnostic codes on the incidence and mortality files.*

Constraints:

- The proposal developmental work will require agreement in principle by directors of provincial cancer registries.

- The national cancer incidence file does currently not include identifiable cancer incidence records for Ontario. These may be obtainable subject to an agreement between Ontario and Statistics Canada concerning use and release of identifying information.
- During the developmental work, it may become necessary to incorporate upgraded information (supplied by provincial cancer registries) into the national file.

Collaboration:

The project will involve collaboration between provincial cancer registries, Statistics Canada and sponsors which may include Health and Welfare Canada and the Atomic Energy Control Board.

From:

"Development of a National Record Linkage Program in Canada", Martha E. Smith, Statistics Canada, 1982

Table 1.—Agencies Involved in Long-Term Medical Follow-up Using Record Linkage.

Kind of Agency and Nature of the Study	Number of Individuals
A. U.S.A. research institution	
1. Ontario morticians (formaldehyde)	1,500
2. Bendix employees	1,700
B. Canadian universities	
3. Breast cancer and age at first birth	300,000
4. St. Regis fluoride study	2,500
C. Labour - management - university	
*5. INCO nickel workers 1940-1976	62,000
6. Falconbridge nickel workers	12,000
7. INCO-Falconbridge - Uranium internal linkage	93,000
D. National Cancer Inst. of Canada	
8. Isoniazid and cancer in tuberculosis patients	64,000
9. Fluoroscopy and cancer in tuberculosis patients	100,000
10. Canadian Labour Force - 10% sample	700,000
11. Railway workers	18,000
E. Provincial Royal Commission	
12. Ontario Uranium miners	16,000
F. Provincial labour depts. & WCB	
13. Ontario miners nominal roll	57,000
G. Crown corporations	
14. Eldorado uranium workers	21,300
15. Atomic energy workers (AECL)	20,000
16. Eldorado Nuclear Limited - Ontario miners internal linkage	73,000
H. Provincial cancer registries	
17. Alberta cancer registry death clearance	175,000
18. Ontario cancer registry reporting system	125,000
I. Federal depts. (including AECB)	
19. Infant death - birth linkage (1971 births)	6,000
20. Newfoundland fluorspar miners	2,000
21. Nutrition Canada Survey participants	20,000
22. Infant birth - death linkage (1978-1980 births)	10,000

*INCO refers to the International Nickel Company.